DRAFT: Recommendations on tackling Perinatal/Infant Mortality

Prof Sushma Acquilla FRCP, FFPH
Independent Chair Birmingham Perinatal and Infant Mortality Task force

Introduction

The overlap between Perinatal and infant mortality, maternal mortality and the maternity services cannot be ignored and a whole system approach is required. These draft recommendations have arisen from the following meetings;

- 1:1 meetings with various stakeholders and key players (28 to date since Oct 21, some outstanding)*

Task Force meetings (8) and other group meetings attended

- Maternity Action Group for West B'ham
- BUMP / LMNS program Board
- Culturally Competent Genetics Services - Funding Bid opportunity BSOL LMNS
- Genetic Risk: Close relative marriage Interactive workshop on the application process
- Culturally Competent Genetics Service Working Group/for bid
- Preventable Deaths Think tank
- Birmingham Solihull CEDOP Strategic meeting
- BSiL subgroup/MAG merged meeting
- Birmingham Children's Partnership Away Day

**So far I have had no success in meeting the Muslim Males and the faith leaders. In process of rearranging these meetings with faith leaders from Birmingham.*

A separate report in tabular form at Annex A summarises the recommendations from the following significant national and local reports:

1) *Seldom Heard; Conversations about Pregnancy,* Birmingham City Council, July 2022
2) *INVISIBLE; Maternity Experiences of Muslim Women from Racialised Minority Communities. A Summary Report*, Shaista Gohir OBE, July 2022
3) *Birmingham and Lewisham African Caribbean Health Inequalities Review (BLACHIR),* March 2022
4) *Women's Health Strategy for England*, Department for Health and Social Care 20 July 2022
5) FIVEXMORE: The Black Maternity Experiences Survey: A Nationwide Study of Black Women's Experiences of Maternity Services in the United Kingdom; Peter and Wheeler, 2022.

~~* PS So far I have had no success in meeting the Muslim Males and the faith leaders. In process of rearranging these meetings with faith leaders from Birmingham.~~

Priority themes, objectives and actions

Below are the broad objectives to improving better care.

1. Research and innovation
2. Co-production and community engagement
3. Implementation

1. Quality, safety and access to services

Objectives	Themes from discussion 1:1
Improving access to the system	Best care for women knowing How and what to do Plenty of good guidance is available but problem with implementation of guidance Move towards "Package of care"
Strengthen preconception care services and engagement	Vitamin D and Folic acid deficiency Non invasive prenatal screening. Holistic support and care for next pregnancy Implementation of good practice Reducing preterm births: pre pregnancy Counselling Pre-conception panel genetics Advice re losing weight before next pregnancy / poverty issue Community side of the care is missing sometimes, hence pre-pregnancy/ pre conception advice is not available.
Increase engagement with antenatal services and promote the benefits of antenatal care	Services are better for high alert patients Care drops after 2nd delivery in hospital Risk assessment best done by Fetal medicine nurse /HV Improving access to the system HBA1C needs to be introduced as routine test in pregnancy. Quality standards in antenatal care are important factors.
Increase awareness regarding genetic services	More education is required in school on preventable causes Rare conditions recorded at delivery but may not be seen as problem – prompt referral Difficult to change as 90% of Consanguineous couples may produce normal child
Training of health care workers and clinicians in cultural compassion	Women feel that there is structural racism and lack of trust and respect. There are superstitions and cultural behaviours that do not help Holistic support and care for next pregnancy get a group of women and arrange meeting to educate them and empower women in decision making
Training regarding postpartum contraception	Implementation of good practice Move towards "Package of care" Need to improve maternal post partum care/ postnatal checks.

Appropriate assessment and referral during pregnancy and support during birth	Services are better for high alert patients Care drops after 2nd delivery in hospital Risk assessment best done by Fetal medicine nurse /HV Non invasive prenatal screening. Risk assessment and risk management
Develop excellence in reducing injury in premature Births[GJ(CHNFT1]	Use literature from other areas like Manchester. Plenty of good guidance is available but problem with implementation of guidance Adverse outcome if born in separate local unit without adequate neonatal support. Adverse outcome for hypothermia in babies at the time of resuscitation. Both can be avoided by complicated/ premature deliveries to be done in Level 3 women's hospital and Transthermot heating pack cover the baby and avoid hypothermia. Monitor breathing cycle during "golden hour" Midwives have an important role for those who have had premature delivery before.

2. Maternal and infant wellbeing

Objectives	Theme group
Support women to stop smoking and promote smoke free homes	Smoking cessation Immediate action could be taken on major risk factors in women i.e. Obesity/ smoking/ diabetes/ socio economic factors Main causes on Infant deaths Obese mothers with high BMI, From deprived area, smoking, Housing issues: overcrowding
Support maternal mental health and wellbeing	Re establish women's centre for exchange of information/ education Re establish children's/ women's Centres like Sure start get a group of women and arrange meeting to educate them and empower women in decision making
Reduce maternal obesity and improve nutrition	More education is required in school on preventable causes Immediate action could be taken on major risk factors in women i.e. Obesity/ smoking/ diabetes/ socio economic factors Main causes on Infant deaths Obese mothers with high BMI, From deprived area, smoking, Housing issues: overcrowding
Encourage and support breastfeeding	What about Health Visitors/ children centres support?

Support families in health and genetic literacy	More education is required in school on preventable causes get a group of women and arrange meeting to educate them and empower women in decision making Service providers need to change attitude Families are now coming forward for tests and new generations are changing. Access to information for young couples Intervention not accepted due to religion and get judged on the decision Adoption and milk bank not accepted in religion Rare conditions recorded at delivery but may not be seen as problem – prompt referral
Alcohol and substance-misuse support during pregnancy and postnatally	

3. Addressing the wider determinants of health

Objectives	Theme group
Support efforts to reduce and mitigate the impact of poverty	Wider public health determinants to be addressed i.e. pollution and Poverty Income poverty and quality standards in antenatal care are important factors.
Housing	Wider public health determinants to be addressed i.e. pollution and Poverty Main causes on Infant deaths Obese mothers with high BMI, From deprived area, smoking, Hosing issues: overcrowding
Identify and address poor environments	Wider public health determinants to be addressed i.e. pollution and Poverty
Working with homeless team to support vulnerable mothers and infants	

4. Safeguarding and keeping infants safe from harm

Objectives	Actions
Safe sleeping	More education is required in school[GJ(CHNFT2] on preventable causes
Safe home environments	More education is required in school[GJ(CHNFT3] on preventable causes

Prevention of injuries	More education is required in school on preventable causes
Reduction in domestic abuse during pregnancy and motherhood	More education is required in school on preventable causes "I can cope" not shaking the baby[GJ(CHNFT4]

5. Providing support for those bereaved and affected by baby loss

Objectives	Theme group
A system-wide approach to making things as easy as possible for bereaved families	counselling for those who have lost a baby-(3 months after)[GJ(CHNFT5]
Strengthen pathways to ensure people who have had a loss receive enhanced support for their next pregnancy	Holistic support and care for next pregnancy Timing for postnatal bereavement 5-6 wks Late loss in pregnancy and stillbirths should be one of the research priorities
Increase the skills and confidence of the wider workforce to talk about bereavement	Timing for postnatal bereavement 5-6 wks

Recommendations

Although the draft recommendations have been circulated earlier to various individuals/ groups, they were discussed fully on 14th October at the Infant mortality and inequality Group. It was decided that these recommendations should be presented in the priority order that can be implemented as soon as possible with appropriate policy and protocols. It was also agreed that these should be presented in tabular form and there should names attached to each of the recommendation, who would take a lead on implementation. The recommendations were reviewed again on 11th Nov.

Recommendation	Lead person	Progress
Ambulance services should convey premature labour cases to a tertiary centre as per national guidance, rather than to the place of booking. Where there are barriers to this happening this should be addressed.	Lisa Stalley-Green/Bump (?WMAS input requested)	Maternity pathway issue *'Ambulances are alerted by hospital leaders if there is a need to divert women away from their original place of booking. Information is also sent out in the daily SitRep based on the Operational Pressures Escalation Levels framework (OPEL) via email across the region. If a hospital is in escalation this is communicated, and alternative arrangements for other tertiary units are found. This may be out of the region, depending on whether the unit is in escalation due to maternal beds or neonatal cots'* Issue appears to be one primarily of bed-space. Meeting to be had with WMAS to gain their thoughts.
Ante-natal steroid use has been shown to be effective in improving perinatal outcomes. This should continue to be tracked and delivery maximised.	Lisa Stalley-Green/Bump	Maternity pathway issue *This is already a standardised antenatal pathway, and is measured on the LMNS monthly dashboard.* Could there be a role for PeriPREM or similar to maximise? (JB)
Thermal Management: Optimal temperature management has been shown to improve outcomes: how are we monitoring effective use?	Lisa Stalley-Green/Bump	Maternity pathway issue *Already in guidelines, (needs to be measured to take up with NN team*)
CDOP enquiry has highlighted delayed cord clamping as involved in a number of it's cases. There should		(Helen Chaplin)

be a review of the policy on this.		
All CDOP problems identified should be followed by identified actions for all preventable deaths. There should be a mechanism to 'close the loop'	CDOP Coordinator – Marion should be able to action through CDOP	*This already happens. After each CDOP meeting letters are written to the appropriate organisation/officer. These are recorded on the minutes and are followed up.*
Data monitoring to be more granular with accurate mapping of causes of deaths, with geographical mapping. This would help identify the preventable and other causes due to congenital abnormalities and population/ areas to focus upon.	As above	*Work with Deepthi Jo Garstang and Marion. Marion to link in with Jo Tonkin the AD in PH with responsibility for data, insight and intelligence.*
Improved access to genetic screening services for those at particular risk (consanguinity) or those who have the history of perinatal loss.	ICS – Lisa in first instance	*Successful bid for a culturally competent genetics service has been awarded, therefore a service will be implemented in the coming months*
Improve delivery and access to Preterm Baby clinics to encourage early booking and approachable parenting. Specific targeting at parts of the community that are less likely to access services should be delivered	Lisa/BUMP	Maternity Pathway *There are already preterm clinics led by consultants within the system for those who have/are at risk of preterm delivery.* *Liaison with external stakeholders will be sought to help reach a wider audience (KRN)* *?Use of local radio was made at initial meeting (JB)*
Additional funds have been announced for 6-8 highest PNM and IM areas. Need to make appropriate bid, ideally in collaboration with other areas to get synergistic effect of any action.	ICS – Lisa S-G	To speak with Kathleen Roche - Nagi
There has been an introduction of nationally funded pilot in 8 areas with Culturally Competent Genetic Service. There should be collaboration with 7 additional sites to enable joint learning.	As above	*Sylvia to follow up*
Consideration of monthly outreach clinics to help consultants working with GPs and reach hard to get community. Connecting with ICS and PCNs is important to get the priorities listed.	ICS – L S-G/BUMP	*Link workers are doing this work already, although there is no specific outreach clinics due to estate, link workers are community based to reach MWs and linking in with GPs, (although work with GPs could*

		be explored further).
Engage with midwives from the clinics where initial booking is happening. Introduce Black companion service to help facilitator role within existing services; Significant legacies need to be tackled as parts of the community feel left behind and frustrated. Implementation of BLACHIR recs is key.	Lisa S/G/BUMP	BLACHIR work being implemented (reword recommendation)
Establishing maternal medicine network. This may include use of Independent midwives	BUMP	MMN established
Need for establishment of Peri-natal Psychology services to help those bereaved with loss of the baby but also to support with the major risk factors identified, where the larger partners from LA should be involved, like poverty/ overcrowding/ smoking.	commissioner leads for MH & Maternity Bereavement midwife leads Cassie	Bereavement pathway is in draft, due for sign off Dec '22 Childrens' plan (link) colin.michel@birmingham.gov.uk
Engagement with Faith and community leaders. This should be broad, not just focussed on e.g. local Imams	Salma Yaqoob has offered to help with this problem working with Kathleen	In progress
Cultural competency training, starting with leadership would be important. Level of cultural competency with an individualised rather than homogenised approach to black communities. Major awareness campaign to be introduced	Need to unpack and discuss, if just in maternity then BUMP, if not then BLACHIR ICS group for NHS and BLACHIR implementation board	Sylvia BLACHIR *Commissioned Culturally competent work is taking place within the trust providers, Sylvia working with a group of parent leaders to find out the specific needs for black women in the community*
Need to have a meeting with appropriate individuals who can bring about a positive change,		Planned meetings with Neonatologists and WMAS

Perinatal Care for Women in minority groups; information brief

Dr J Barnes, GPST1

Introduction

This Annex forms part of the context of the task force set up in Birmingham to address the higher rate of perinatal mortality in the region. At the time of writing (Autumn 2022), a number of reports had been commissioned both nationally and regionally which each shone light on different aspects of perinatal care for pregnant women from a number of backgrounds. This brief aims to summarise these reports to establish a grounding.

Sources:

1) *Seldom Heard; Conversations about Pregnancy,* Birmingham City Council, July 2022
2) *INVISIBLE; Maternity Experiences of Muslim Women from Racialised Minority Communities. A Summary Report*, Shaista Gohir OBE, July 2022
3) *Birmingham and Lewisham African Caribbean Health Inequalities Review (BLACHIR),* March 2022
4) *Women's Health Strategy for England*, Department for Health and Social Care 20 July 2022
5) *FIVEXMORE: The Black Maternity Experiences Survey: A Nationwide Study of Black Women's Experiences of Maternity Services in the United Kingdom*; Peter and Wheeler, 2022.

Theme	Seldom Heard Voices	Invisible	BLACHIR	Womens PLAN	FIVEXMORE
Access to Healthcare	Access to healthcare generally worse than population as a whole, but difficulty especially in accessing resources related to sexual and reproductive health (SRH). Particular barriers are social (stigma of attending services, linguistic (not having resources translated, or translations being out of date), and digital exclusion (with limited access to internet) being an issue.	Despite increased population risks of certain maternal complications, the report felt that 'additional screening is not being offered' (p18). Where screening was offered, it wasn't specific to individual risk for their ethnic group.	"Women were not provided with sufficient antenatal education" (p18)- Significant barriers such as under-resourcing of services and difficulty in accessing midwives impacted women's health. Recommendation: 'Promote health checks through public campaigns to increase the uptake of community-based health checks in easy to access locations' (p10)	"Fragmented commissioning and delivery of (SRH) negatively impacts women's access to services." (p25) Not specific to Birmingham, but having to attend multiple different services negatively impact outcomes. Strategy Goal: 'Women are supported through high quality information and education to make informed decisions about their reproductive health, including if and when to have a child' p68	Although few barriers to accessing healthcare were identified, the quality of advice was a drawback. Many felt uninformed about risks, and felt a sense of 'dismissiveness' about their concerns. Concerns were raised about access to screening eg for sickle trait, and generally for accessing pain relief.
Cultural Differences	Some Muslims view problems in pregnancy being 'the will of Allah' was seen, with similar approaches to contraception. Conversely, when things went wrong with a pregnancy, some felt that they were blamed, and felt unsupported emotionally by partners and family. On male partners, some identified contraception as the 'woman's job', and poor understanding of pregnancy meant a lack of support for mothers. Cultural factors such as religion, beliefs and values played a significant amount for some, with the view of elders being held in high regard. Often this was poorly understood by HCPs and not reflected in their causing an extra barrier.	Significant concerns were raised about unconscious bias of merging all of the various Muslim communities under one label, causing a barrier to effective healthcare. Of note, less than 40% of staff were reported as having good or very good 'knowledge of the culture of the women they served' (p17).	Maternity Care Processes do not recognise cultural differences between black African and Black Caribbean women' (P38).		A lack of sensitivity towards cultural experiences of pain seemed to be a common theme. Broadly, recommendations for addressing unconscious bias were made, with concerns about instances of inappropriate jokes made.
Health Communication	Barrier to communication from lack of information in own language, or language that isn't up to date. Poor access to interpreters can also be a significant issue. Also some issues with the ways in which HCPs present information, with some 'feeling judged for wanting more children'	Women "were not provided with sufficient antenatal education", putting them and their babies at risk (p15). Women felt pressured to 'accept interventions' such as induction of labour (p21). Throughout report not being listened to was a recurrent theme.		"84% of (Women report) instances in which they had not been listened to by healthcare professionals." (p15)	Although there seemed to be good access to antenatal advice re: physical health, there was limited Mental Health input- 40% weren't asked about their mental wellbeing. Women in the study wanted HCPs to 'listen…without making assumptions'

Sources of Information	Significant amount of peer and community teaching, often different to NHS advice. Some felt that they would only need information about contraception later on in life and would seek it out then. Lack of access to internet services and 'digital exclusion' was particulary prevalent in some communities. Suggestions for the kind of service that would be beneficial was the option for pre-conception clinics, especially ones embedded within the communities involved.	56% using Friends and family for source of info (p15)	Suggestion: 'develop targeted programmes on health literacy for 'Black african and Black caribbean communities' (p10)	Family and friends main source of information (74%) (p21)	60% of women surveyed had accessed e.g. the NHS website as a source of information.
Outcomes		Significant Gaps in data because of lack of ethnicity data and no disaggregation into smaller groups. (p32)	Black women 5* more likely to die in pregnancy or childbirth than white women (p34) Highest infant mortality rates... in the Carribbean and Central Afric(an)' communities. Concerns about significant lack of data on these communities, lack of 'lived experience'		27% felt that their overall care was either poor or very poor. One key recommendation was for more community-based midwifery input.